



Public awareness and understanding of mental illness has grown over recent years, due in large part to educational initiatives and assistance offered to those affected by it. While helpful, these efforts have focused primarily on the general population; the public might not be as aware that people with intellectual and/or developmental disabilities (I/DD) are as susceptible to mental illness but do not always have access to the same level of treatment and support. Communication barriers, funding concerns, and misconceptions about I/DD can obstruct efforts to ensure equal and needed access to mental health services.

This edition of the *HCQU CARES* newsletter presents information caregivers can use to support people with "dual diagnosis" – diagnosed with both I/DD and a mental health condition – to obtain access to quality services and experience their best "everyday lives." This includes signs that indicate a person with I/DD is experiencing symptoms of mental illness; ideas that can help an individual's psychiatrist determine accurate diagnosis and effective treatment; the effects trauma can have on the mental and emotional health of someone with I/DD and supportive strategies; and the importance of advocating for an individual to receive quality care.

In addition, the KEPRO HCQU is excited to introduce Kim Mathos, D.O., M.P.H., as a consulting psychiatrist. Dr. Mathos is a clinical assistant professor of psychiatry at the University of Pittsburgh. She has extensive experience working with individuals in the deaf, deaf-blind, and hard-of-hearing population, as well as experience serving individuals with I/DD. She is passionate about developing and promoting community recovery programs. Her expertise will be a valuable and helpful addition to the work of the KEPRO HCQU.



# Advocating for Effective Treatment for Individuals WITH DUAL DIAGNOSIS

By: Kim Mathos, D.O., M.P.H. (edited by Brian Leech, MS)

Over the past fifty years, there have been tremendous changes in the way that people with intellectual disabilities have received supportive services. Many community services have been created to meet the housing and day programming needs of individuals and their families. However, for individuals diagnosed with mental illness and I/DD, quality treatment has sometimes been difficult to find. Prior to the 1960s, it was thought that people with intellectual disabilities did not experience conditions like depression, anxiety, attention deficit disorder, bipolar disorder, or psychotic illness. Mental illnesses for those with I/DD were seen simply as behavior or social concerns rather than psychiatric conditions. Since then, it's become understood that people with I/DD can and do experience mental illnesses, just as those without I/DD. The term "dual diagnosis" is now used to describe individuals who have an intellectual or developmental disability and a mental illness/mental health condition.

Estimates state that between 14 and 70 percent of people with I/DD also have mental health conditions. People with I/DD may have higher rates of mental illness due to premature birth, exposure to substances while in the womb, a difficult or traumatic birth, exposure to infections, or genetic differences that change the brain's structure or functioning. In addition, negative social issues can impact the mental and emotional health of someone with I/DD. Experiencing rejection by peers, low self-esteem, or bullying can all affect the development of the brain and of one's coping abilities. Rates of abuse are also higher among people with I/DD. Several studies have found that between 50-85 percent of women and 25-50 percent of men with I/DD have been sexually assaulted by age 18 (Werges, 2007).

People with I/DD can continue to experience difficulties into adulthood. Finding safe and stable housing, enjoying meaningful relationships, having purposeful employment, and something of worth to do each day can be a challenge for those who are dually diagnosed. These factors lead to stress and anxiety, feeling "less than" others, anger, and depression. They can also contribute to the development of chronic mental illness; in fact, many professionals who work with those with I/DD see individuals who have trouble managing emotions, sleep problems, sadness, a lack of impulse control, and even symptoms like hallucinations (seeing, hearing, feeling things that are not really present) and delusions (for example - believing oneself to be "God," or that he/she is being followed by government agents).

Caregivers who work with individuals may not always realize that mental illness can be a factor in challenging behaviors. For example, a caregiver might believe that if a person was "less moody," or "less anxious or angry," they would be more fun to be with or easier to take on outings. Initially, these behaviors may not be seen as a possible mental health condition – even by medical and psychiatric professionals. That can delay a person's treatment and contribute to worsening symptoms. Consider the story of Ronnie, who has gone through these kinds of delays.

### The Story of Ronnie:

Ronnie is a 28 year old man who was abandoned by his birth mother as an infant. Growing up, he moved from one foster home to another in a rural county, with foster families typically saying that they could not handle his challenging behaviors. In school, he struggled to fit in and was regularly in detention or suspended. He dropped out of school in tenth grade, and soon afterward, Ronnie became homeless. He ended up living in a vacant barn, and for a while, his presence was tolerated by the landowner until he began to drink alcohol. On several occasions when he was intoxicated, Ronnie yelled at and threatened the neighbors. Finally, the police were called and Ronnie was arrested. He attempted suicide in jail and was sent to a psychiatric facility, then was placed in an emergency shelter. After several months, he was finally moved to a group home.

At the group home, Ronnie punched several of his caregivers and even broke one's nose. As these challenging behaviors continued, it became harder to persuade caregivers to work with him. Those who remained at the home took notes on what they saw and heard; this helped Ronnie's treatment team to identify triggers to his episodes of anger. Caregivers also noted times when he was calm and what was happening that seemed to help him stay relaxed – this allowed the team to think about interventions that would make sense for Ronnie.

With the observations made by caregivers, a review of old medical records, and tracking of behavior and mood states, the psychiatrist was able to identify a proper diagnosis. Ronnie began treatment with medications and learned behavioral strategies to manage his anger. Eventually, the treatment team and Ronnie learned how to respond to his episodes of anger, and how to help him head off those episodes before they became challenging. Through good communication between caregivers, the psychiatrist, the behavior specialist, and the therapist, Ronnie began to feel calmer and happier in his new home.

Ronnie's caregivers now love working with him, and he enjoys a host of different activities in the community. He is able to enjoy his time with his peers and has made several new friends. Ronnie also got a job cleaning part time, and each month he saves a small amount of money to spend on activities with his friends or items he wants to buy.

Ronnie's story shows what rehabilitation and recovery can look like for a person with intellectual disabilities and mental illness.

If you are worried about the mental health of a person with I/DD, be sure to monitor and report any concerning symptoms or behaviors to the person's treatment team. Some other ideas that can be helpful include:

- Asking family members about any noticeable changes in mood, sleep, interests, or thinking patterns.
- Investigating the possibility of a family history of mental illness (many mental health conditions are heritable).
- Considering if the person is experiencing any new health conditions which can exacerbate anxiety, depression, or unusual behaviors.
- Observing whether any new medications have led to changes in a person's mental state.

- Talking to the person about how they are feeling; ask the person what could be helpful in trying to feel better (when possible).
- Encouraging activities that the person typically enjoys.
- Assessing for new stressors, bullying/abuse, or dissatisfaction with life.
- Noting any changes in memory or independent living skills/activities of daily living.

To find providers who regularly support people who have dual diagnosis, call the member services number on the person's insurance card. It is also good practice to discuss concerns with the person's supports coordinator or family physician.



# Behavioral Signs of MENTAL ILLNESS

By: Brian Leech, MS, Clinical Educator

Recognizing signs that a mental illness is present and/or worsening in a person can be difficult, because people with the same illness can experience different symptoms and demonstrate them in different ways. Additionally, healthcare providers and caregivers may misattribute the signs of mental illness as being caused by I/DD (this is known as 'diagnostic overshadowing'). For example, one person with bipolar disorder (an illness that involves phases of high and low moods) might hear voices when experiencing the high moods associated with mania, while another may simply become more talkative and restless than usual. Identifying symptoms of mental illness in a person diagnosed with I/DD can be even more challenging; people not familiar with the person might not regard changes in behavior as possible indications of mental illness. Learning as much as possible about an individual with I/DD – including personal history, experiences, and usual behaviors – can prepare caregivers and other professionals to recognize behavioral signs that a person is experiencing symptoms of mental illness.

It is important to distinguish between the terms "symptom" and "behavior." Symptoms are changes in a person's normal functioning due to an illness or a condition (Nordqvist, 2018). If the illness were not present, the changes would not occur. Behaviors, on the other hand, are ways a person reacts and responds to events or situations (American Psychological Association, 2018). Behaviors are the observable signs (i.e. people's actions) that an illness is present.

Examples of symptoms and behaviors can help to clarify the difference. A "runny nose" is a *symptom* of a cold – a change in the usual functioning of the person's body caused by illness; without the cold, the person would not have a runny nose. In response to the symptom (runny nose), the person sniffles or blows her nose. These *behaviors* indicate the person is experiencing a symptom of a cold. Likewise, a person with schizophrenia (a mental illness that can involve hallucinations – seeing, hearing, feeling, tasting, or smelling things that are not actually present) may hear voices commenting on everything he does. "Hearing voices" is a *symptom* of schizophrenia; without schizophrenia, the person would not hear the voices. In response to the symptom (hearing voices), the person may suddenly change what he is doing and respond aloud to comments no one else can hear. These *behaviors* indicate the person is experiencing a symptom of schizophrenia.

General behaviors caregivers might observe when a person with I/DD experiences symptoms of a mental

#### illness include:

- Marked personality change Current behaviors are out of character for the person. For example, a person who typically is quiet and reserved is observed yelling at caregivers and others repeatedly.
- **Difficulty coping with problems and daily activities** The person might refuse to participate in outings, see others, or go to work/day program.
- **Strange or grandiose ideas** The person might talk about people listening to his or her thoughts, or claim to have talents or abilities that nobody else has.
- Excessive anxieties The person might worry about which caregiver will be coming to work, ask questions over and over despite getting the same answer, or appear to be afraid (or 'on edge') most of the time.
- **Prolonged depression and apathy** The person stays in bed, cries frequently, or does not show interest in games or hobbies that she or he used to enjoy.
- Marked changes in eating or sleeping patterns The person might begin to awaken during the night and appear tired through the day, eat constantly or refuse to eat, or express fatigue or digestive issues.
- Thinking or talking about suicide or harming oneself The person might express thoughts about self-harm, others dying, what it is like to be dead, or wishing never to have been born.
- Extreme mood swings The person might appear happy one minute and angry, irritable, or sad the next.
- **Abuse of alcohol or drugs** For people with I/DD, this can include increased requests for medication.
- Excessive anger, hostility, or violent behavior The person might fight with others, make threats to other people, and/or demonstrate extreme anger with little provocation (American Psychiatric Association, 2018; National Institutes of Health, 2007).

Individuals who have limited language skills or do not speak might demonstrate additional behaviors in response to symptoms of mental illness. According to a list compiled by psychiatrist and I/DD researcher Ruth Myers, these behaviors can include:

- Staring to the side or into a blank space, nodding and gesturing as though hearing conversation others do not hear.
- Appearing to fight and/or shadow box with unseen others.
- Unusual sexual activity.
- Brushing away unseen items.
- Wearing multiple layers of clothing.
- Coving one's eyes and/or ear.
- Placing unusual wrapping (such as feminine hygiene products) around the ankles or wrists, in the ears, or

over other "openings."

- Glaring with anger and intensity at previously liked people or strangers.
- Wrapping bandanas or scarves around the head, though not compatible with the rest of the person's clothing.
- Wearing costumes inconsistent with any known role in reality.
- Inspecting food and beverages with extreme and exaggerated suspiciousness and/or intensity.
- Grimacing or wincing, as though tasting something bad.
- Spinning or running in circles to the point of collapse.
- Hiding from familiar, previously trusted people (Myers, 2017).

Other possible causes of behaviors – physical pain or discomfort, environmental factors, and past experiences – must be ruled out before a person's behaviors are attributed to mental illness, especially if the person is not able to talk about or describe what he or she is experiencing. Caregivers can take the following actions to rule out other causes:

- Request a physical examination of the person by the primary care physician to rule out medical concerns.
- Review the person's medications with the physician to identify medication side effects or interactions that might contribute to pain and discomfort.
- Consider where and with whom behaviors occur to identify if the behavior is related to a specific location, situation, or person/people.
- Know the person's history and experiences, especially if there is a history of trauma or abuse. Past experiences can leave powerful and lasting impressions, especially if the person does not have the coping skills or resources to recover from the event. These experiences can contribute to challenging and/or unusual behaviors long after the trauma has occurred (Myers, 2017).

By reporting observations of a person's behaviors in a variety of situations, caregivers enable the person's treatment team to examine the behaviors and determine if they indicate the presence or worsening of a mental illness, trauma/abuse, medical concerns, and/or environmental factors. Identifying the cause(s) of the behaviors allows the team to select effective interventions to support the person to live a healthier and fuller life.

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By: Erin Sass, Clinical Educator

According to the 2012 National Survey on Abuse in People with Disabilities, over 70% of the people responding to the survey reported being victims of abuse (Baladerian, Coleman, and Steam 2013). Additionally, 34.2% of the people with I/DD responding had experienced sexual abuse, and the majority of them said that it had happened more than once (Baladerian, Coleman, and Steam 2013). This highlights the importance for caregivers and professionals to understand the meaning of the term "trauma" and the effects trauma can have on the lives of people with I/DD.

Trauma is an emotionally painful or distressing experience involving a threat to a person's well-being or survival. The human body uses built-in coping skills for protection against threats, including the "fight, flight, or freeze" responses, in which a person may attempt to fight off a threat, run to safety (flight), or become overwhelmed by the threat and have difficulty reacting to it (freeze). However, a person who has experienced the stress of severe or long-term exposure to trauma might not be able to "switch off" these responses. In fact, the need to continually defend oneself from psychological and physical stress can lead to the development of mental and physical disorders (Bloom, S. L. 2014; Marcal and Trifoso 2017).

A person who has experienced trauma might rely on destructive or combative behavior to feel safe, manipulation to feel a sense of control, and/or self-injury to feel relief from painful emotions. If the behaviors become the person's default responses to daily challenges, they are considered "longstanding behaviors." For people with I/DD, longstanding behaviors are defined as severe, long-term, treatment-resistant, and are typically seen as only behavioral (Myers and Myers, 2017). Though it might appear as if the person engages in these behaviors intentionally, the behaviors are involuntary.

Examples of longstanding behaviors include:

• Persistent re-experiencing behaviors — Commonly referred to as "flashbacks", these behaviors occur when a person believes trauma experienced in the past is happening in the present. Physical reactions might include faster breathing, increased heart rate, and a "fight, flight, or freeze" response. A person who starts striking at those around him might believe he hears the abuser's voice and must protect himself. A person who insists her arm is injured when there is no evidence of physical injury might believe she just experienced being punished by having her arm twisted, a punishment she actually received as a child.

- Avoidance behaviors These are behaviors that prevent a person from being reminded of a traumatic event. A person who was injured or restrained during a past medical exam may now "act out" prior to a doctor's appointments. A person may use self-injurious behavior to avoid feeling the emotional pain of a traumatic event (Myers and Myers, 2017).
- Hyperarousal behaviors Hyperarousal is the body's way of staying prepared even though the threat is no longer present (NCBI Bookshelf, n.d.). Hyperarousal behaviors can include sleep disturbances, muscle tension, being easily startled, and a lower threshold for stress. Hyperarousal might help a person feel safer after a traumatic event, but over time it can cause a person to view everything as a threat and to never feel safe.

A person who does not receive treatment following severe trauma or abuse can experience the effects of that trauma for many years. They might be vulnerable to further abuse, hypersensitive to changes in their environment or the perception of others' judging them, and easily influenced by triggers (Vitelli, 2013).

In her book *Individuals with Intellectual Developmental Disabilities and Aggression, Self-Injury, and/or Failure to Thrive: One Comprehensive Approach*, Ruth Myers, M.D., discusses six treatment protocols for supporting people with I/DD who may be experiencing the lasting effects of trauma.

- 1. Careful use of medications The goals of medication in treating the effects of trauma are to reduce painful symptoms, treat co-occurring conditions, and maximize the person's level of functioning. Long-term use of medications prescribed for treating aggression may interfere with healing.
- 2. Careful and complete medical evaluation and treatment People who have experienced trauma require a gentle approach during treatment of medical needs, which includes respect for privacy and boundaries. The American Academy of Developmental Medicine and Dentistry (AADMD) offers ideas for preserving people's privacy and respect during medical examinations.
- 3. Appropriate psychotherapy Psychotherapy for people with I/DD works best when it is individualized to meet the person's needs. Look for a therapist who is familiar with a variety of communication styles and therapeutic approaches. Some goals of therapy for a trauma survivor include helping the person communicate about the trauma to someone who can respond appropriately, recognizing the impact the trauma has had on the person's life, emphasizing the person's strength and power, and deciding how much of the past can influence the present.
- 4. Reduction of harm caused by treatment This refers to reducing triggers in the person's environment and relationships. Ways to limit harm in treatment include:
  - a. Avoid perpetrators.
  - b. Develop behavior support plans focused on comfort and flexibility, rather than control and compliance.
  - c. Talk with the doctor about medications that do not seem to be helping, especially ones that cause sluggishness or dullness.
  - d. Support the person's choice of caregivers and their shifts, to the extent possible
  - e. Avoid situations that might cause humiliation.
  - f. Assist the person to maintain space and privacy from roommates, especially if the person did not choose the roommates.

- g. Explore ways to make daytime programs and activities meaningful to the person.
- h. Find medical providers who are respectful of the person's boundaries.
- 5. Making habilitative changes Create an environment that is comfortable, safe, and conducive to the person's needs and preferences.
- 6. Caregiver training and support Educate caregivers about trauma and its effects, the person's history, and effective methods for supporting a trauma survivor. Train caregivers and other team members on a support plan that is specific to the person's needs and promotes a safe environment (e.g., avoiding triggers, offering choices, respecting privacy and boundaries, and using positive communication/approaches) (Myers and Myers, 2017).

The long-term effects of trauma can interfere with healthy functioning and intensify everyday situations into potential crises. Determining the extent of trauma a person with I/DD has experienced can be challenging. However, longstanding behaviors that do not improve with medications are often reliable indicators of trauma. There are strategies available for caregivers and clinicians to use to support the person to live a full and healthy life.

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By: Elizabeth Hobbs, Clinical Educator

For people with I/DD and mental illness, psychiatric clinicians (such as psychiatrists, psychologists, and therapists) rely on information from the individual, caregivers, and others to enable them to understand the individual's complex clinical picture and develop effective treatment and support methods (KEPRO, 2018). In effect, caregivers often act as the "eyes and ears" of the clinicians. This role enables a caregiver to optimize psychiatric appointments to improve the quality of care for the individual.

## **Before an Appointment:**

A caregiver can gather information about various aspects of an individual's life, such as sleep, appetite, behavior, and mood. This information is most valuable to a clinician when presented in an objective and complete manner.

Objective information consists of observations – pieces of information gathered through one's senses – not influenced by interpretation and/or assumption (KEPRO, 2018). The goal is to use words to communicate how the scene looked and sounded that will enable the clinician to see and hear what transpired, similar to telling someone a story.

"Suitcase" words, or words "packed" with more than one meaning and open to interpretation, do not communicate clear, objective descriptions. For example, "aggression" can have different meanings to different people. One person might apply the word only in reference to a physical attack; others have a broader interpretation that encompasses both physical and verbal attacks (e.g., swearing at others). Observations described in terms of what was seen, heard, and felt – "She spits her pills into the toilet, while saying loudly 'These make me feel bad!" – are more precise and meaningful for a clinician than, "She is non-compliant with taking her medicine."

Including the following details about observations can help a clinician diagnose with more accuracy:

- Onset: When did the behavior or symptom start? Is this the first time the person has demonstrated the behavior or experienced the symptom? If noting the onset of a change in an existing behavior or symptom, describe the change has it increased or decreased compared to previous occurrences?
- Frequency: How often does the behavior or symptom occur? For example, if the symptom is trouble

sleeping, how many nights in the past month did the person have trouble sleeping?

- <u>Intensity</u>: How much does the behavior or symptom affect the person and/or others? For example, is the person engaging in the behavior often or hard enough to hurt self or others?
- <u>Timing/Pattern(s)</u>: When does the behavior or symptom occur? For example, when does the person seem the most tired? At what point in the day does the behavior seem to be most challenging? Are there any patterns, episodes, symptoms, or cycles of behavior that caregivers have noticed?

Contextual (related) information can offer a clinician greater insight into what is causing a behavior or symptom. For example, when reporting a person's mood, it might be helpful to add that the person's favorite caregiver recently resigned. However, assumptions about the cause of the behavior or symptom – e.g., "He is depressed because his favorite caregiver left." – are *not* helpful. It may be clearer and more direct for caregivers to simply report their observations and other information.

Types of contextual information often useful to a clinician include:

- <u>Biological factors</u>: health conditions, current medications (including name and dosage), medical test results, personal and family history
- <u>Psychosocial factors</u>: stressors the person has experienced, including changes and losses; family dynamics; where and with whom the person lives and socializes; and where the person works and/or attends events
- <u>Trauma</u>: types of trauma experienced, if trauma history exists

A clinician needs as holistic a picture of the person as possible. If the person spends time at school, work, or in the community, caregivers may consider including observations of the person in those environments. Ideally, all members of a caregiving team will document their observations and knowledge of the information mentioned above for use during the appointment. However, though most clinicians welcome information, few have time to read more than a few paragraphs about a person. Documentation of observations for clinicians is most useful when it is concise, capturing the most important points about the individual without unnecessary details and assumptions.

## **During an Appointment:**

To assess the person's health, the clinician will likely want to interact directly with the person during an appointment. However, if the person is unable to describe what he or she is feeling, the clinician relies on input from those who know the person to develop a clearer understanding of what is happening; caregivers often are the ones asked for such input.

Clinicians have personal preferences, philosophies, styles, and experiences that influence how they approach and conduct appointments. One clinician might speak with the individual and caregiver separately, asking the individual questions, then asking the caregiver similar questions. Another clinician might prefer to meet with the individual and caregiver together, asking the individual questions, then asking the caregiver for information or observations. Yet another might prefer to obtain information from the caregiver first, then speak with the individual. Caregivers can support the individual's needs by being prepared and flexible, asking questions, and offering suggestions for accommodating the individual's needs. However, there may be times when individuals do not feel comfortable with the clinician; this would be an ideal time to explore other clinicians to find "the best fit," or one that the individual will feel comfortable seeing.

It is not unusual for individuals to be hesitant, even frightened, when a caregiver shares information about a

sensitive topic with a clinician, especially if they feel the caregiver is doing it to "tell on" them or get them "in trouble." If the information involves trauma experienced by the individual, such discussions can trigger intense emotions. If a caregiver asks the individual for permission to share such information before presenting it to the clinician, the caregiver conveys respect and sensitivity for the individual. This simple act (1) acknowledges that the information might be difficult for the individual to hear and/or discuss, (2) communicates the caregiver's intent is to support the individual, not to "tell on" or get the individual "in trouble", (3) empowers the individual with choices about if and how the information will be shared, and (4) might reduce the intensity of emotions the individual experiences during the discussion.

Examples of statements caregivers might use to request permission to introduce a sensitive topic include:

- "If it's okay with you, I'd like to tell the doctor about some concerns I have."
- "I need to tell the doctor about the incident that happened. Is it okay for all of us to talk about it?"
- "We are worried about you, especially because of [name the concern]. Is it okay for all of us to talk about it so we can help you feel better?"

Remember that the appointment is about the individual and his or her health. Therefore, it is a good idea to try to involve the individual as much as possible in any discussion. Encourage the person to ask questions (if he/she is able to and comfortable doing so). Just as importantly, encourage the clinician to talk to the person and not about the person. While caregivers can provide clarifying information at times, the individual can benefit from talking with the clinician, both in terms of building a good relationship and in feeling a sense of empowerment over his or her care.

Appointments with clinicians are opportunities for individuals and caregivers to ask questions for clarification about the diagnosis, treatment, and expected results. Some questions to consider include:

- What is the desired effect of the prescribed medication?
- What side effects might the medication produce?
- How long does it take for this medication to take effect?
- What problems should be reported to you or your office right away if they happen? (e.g., suicidal thoughts, medication side effects, etc.)
- How do we contact you or your office if there is an immediate concern that needs addressed prior to the next appointment?
- What information about the person (such as sleep, appetite, or mood) would you like us to bring to the next appointment?

"What if?" style questions that invite the clinician to reflect can be a powerful tool in treatment. Questions such as, "What if the person receives treatment in an ideal setting, with ideal support; what would treatment look like?" Such questions might prompt changes in support and treatment that improve the person's life.

# **After an Appointment:**

Following each appointment, caregivers can

• Document and update other caregivers with regard to the clinician's diagnosis, treatment instructions, prescribed medication(s), observations to track, and concerns to report.

- Gather the information the clinician requested for the next appointment (e.g., help the person track his or her mood, or complete a sleep chart, etc.).
- Observe for and document concerns noted by the clinician, such as medication side effects.
- Contact the clinician's office with concerns the clinician identified as requiring immediate attention.

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